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Award Number: DAMD17-99-1-9310

TITLE: National Native American Breast Cancer Survivor's Network

PRINCIPAL INVESTIGATOR: Linda Burhansstipanov, Ph.D.

CONTRACTING ORGANIZATION: National Indian Health Board
Denver, Colorado 80222-3327

REPORT DATE: September 2002

TYPE OF REPORT: Annual

PREPARED FOR: U.S. Army Medical Research and Materiel Command
Fort Detrick, Maryland 21702-5012

DISTRIBUTION STATEMENT: Approved for Public Release;
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REPORT DOCUMENTATION PAGE

*Form Approved
OMB No. 074-0188*

Public reporting burden for this collection of information is estimated to average 1 hour per response, including the time for reviewing instructions, searching existing data sources, gathering and maintaining the data needed, and completing and reviewing this collection of information. Send comments regarding this burden estimate or any other aspect of this collection of information, including suggestions for reducing this burden to Washington Headquarters Services, Directorate for Information Operations and Reports, 1215 Jefferson Davis Highway, Suite 1204, Arlington, VA 22202-4302, and to the Office of Management and Budget, Paperwork Reduction Project (0704-0188), Washington, DC 20503

1. AGENCY USE ONLY (Leave blank)	2. REPORT DATE September 2002	3. REPORT TYPE AND DATES COVERED Annual (1 Sep 01 - 31 Aug 02)	
4. TITLE AND SUBTITLE National Native American Breast Cancer Survivor's Network		5. FUNDING NUMBERS DAMD17-99-1-9310	
6. AUTHOR(S) : Linda Burhansstipanov, Ph.D.			
7. PERFORMING ORGANIZATION NAME(S) AND ADDRESS(ES) National Indian Health Board Denver, Colorado 80222-3327		8. PERFORMING ORGANIZATION REPORT NUMBER	
9. SPONSORING / MONITORING AGENCY NAME(S) AND ADDRESS(ES) U.S. Army Medical Research and Materiel Command Fort Detrick, Maryland 21702-5012		10. SPONSORING / MONITORING AGENCY REPORT NUMBER	
11. SUPPLEMENTARY NOTES			
12a. DISTRIBUTION / AVAILABILITY STATEMENT Approved for Public Release; Distribution Unlimited		12b. DISTRIBUTION CODE	
13. ABSTRACT (Maximum 200 Words) The Native American Breast Cancer Survivors' Support Network (DAMD17-99-1-9310) is a three year-project supported by the Department of Defense. This project is being conducted by Native American Cancer Research in collaboration and partnership with the National Indian Health Board. The purpose of this project is to improve the survival from breast cancer and quality of life after being diagnosed with breast cancer for both the patient and loved ones of the cancer patient. The study objectives follow: (a) using key and well recognized Native American cancer leaders from geographically diverse regions of the country, identify and recruit Native American breast cancer patients into the survivors' network and database; and (b) refine, and evaluate the survivor's database to determine patterns of disease and patterns of care experienced by Native American breast cancer survivors. The intended population is Native American breast cancer patients, both genders, ages 20 and older, living anywhere on the North American continent. Preliminary findings include documentation that Native breast cancer survivors are not receiving quality care, less than one-third have access to insurance (and thus access to improved quality of care) and standard protocols used with other survivors are ineffective with Native cancer survivors.			
14. SUBJECT TERMS: breast cancer, survivors, American Indians, Alaska Natives		15. NUMBER OF PAGES 13	
		16. PRICE CODE	
17. SECURITY CLASSIFICATION OF REPORT Unclassified	18. SECURITY CLASSIFICATION OF THIS PAGE Unclassified	19. SECURITY CLASSIFICATION OF ABSTRACT Unclassified	20. LIMITATION OF ABSTRACT Unlimited

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4. Introduction

The Native American Breast Cancer Survivors' Support Network (DAMD17-99-1-9310) is a three year-project supported by the Department of Defense from March 2000 through February 28, 2003 (grant period approved by DoD April 10, 2001). This project is being conducted by Native American Cancer Research in collaboration and partnership with the National Indian Health Board, Mayo Clinic's, "Spirit of E.A.G.L.E.S." and the Native CIRCLE.. The project addresses various support issues for those dealing with breast cancer and to learn more about how cancer is affecting Native communities. The purpose of this project is to improve the survival from breast cancer and quality of life after being diagnosed with breast cancer for both the patient and loved ones of the cancer patient. The study objectives follow: (a) Using key and well recognized Native American cancer leaders from geographically diverse regions of the country, identify and recruit Native American breast cancer patients into the survivors' network and database; and (b) Refine, and evaluate the survivor's database to determine patterns of disease and patterns of care experienced by Native American breast cancer survivors. The intended population is Native American breast cancer patients, both genders, ages 20 and older, living anywhere on the North American continent.

5. Body

According to the previous project director, there are 360 women enrolled in the Network. Our IRB annual renewal was submitted to the University of Colorado Multiple Institutional Review Board (COMIRB) on February 14, 2003. The witness listening in during implementation of the informed consent process continues to be a significant barrier to enrollment in the Network. As for all previous reports, we respectfully request that this DoD mandate be removed. It continues to create feelings of distrust in the patients and is a challenge for staff who implement the informed consent process from home where no witness is available and/ or where there is only one phone in the home. Based on continued issues raised regarding the inaccuracy of medical records (formerly regarded as the "gold standard" by the P.I.), the patients rarely agree to provide the signed medical release for their cancer-related medical records. In the era of HIPPA, and due to the exceptionally high percentage of medical records with missing and inaccurate data, the Network staff have requested that this segment of the informed consent be removed, which we have done so for the 2003 annual renewal.

Task 1: Refine the plan for active recruitment into the survivors' database for all participants of the Social Network, Months 1-3

- a. **Review pilot data from on-going Komen/Breast Ca Fund survivors' network project**
- b. **Modify intake instrument based on Advisory Board's recommendation**
- c. **Modify survivor's computer intake and follow-up database program to be consistent with revised intake instrument**
- d. **Co-investigators train data manager**
- e. **Modify consent form based on Advisory Boards recommendation**
- f. **Submit application to COMIRB**
- g. **Train site coordinators on confidentiality and intake data protocols.**

Progress to Date: All of the above have been accomplished. We have continued to refine the recruitment plan and now encourage volunteer referrals from community members. This is proving to be a better source of recruitment than were key leaders and Native organizations or Cancer Centers.

Task 2. Collection of Survivors' Intake date, Months 4-33

- a. **after receiving the breast cancer survivor referral, the site coordinators and PI contact the patient and collect informed consent and intake data. 30-minute phone cards will be mailed to those Native Americans who do not have phones. Estimate 100 survivors in Year 1, 200 in Years 2 and 3.**

We continue to have difficulties collecting the "witness" during informed consent for the same reasons as specified in September 2000 and 2001 reports:

- (1) To maintain privacy:
 - a. The patient usually prefers to be alone for the telephone interview
 - b. The NACR staff typically implement the informed consent and surveys from their homes to insure privacy during the calls. For most, there is no one else in the household over the age of 18 who can legally sign as a witness. In other homes, there is no second phone. When NACR staff have attempted to have other family members or friends of the patient serve as witness, these individuals may not know of the diagnosis (thus this process of having a witness on line violates both privacy and confidentiality)
- (2) The DoD mandate implies access to more than one phone. However, in many of the households (of both the patient and the interviewer), there is only one phone in the household. In addition some of the patients use a pay phone to call us and thus there is no witness accessible;
- (3) The interviewer must make the call from a confidential setting, which is typically from her home when she is alone--thus no witness is available
- (4) The DoD mandate for having this witness on the phone while the informed consent is being delivered is perceived as the DoD distrusting the honesty and ethics of our staff. In addition, patients has asked the staff what we did to deserve such an invasive mandate (e.g., raises distrust of the staff by the patients)

The DoD response continues to state that NACR has not provided a suggestion for how to handle this barrier. Indeed we have repeatedly made the same suggestion: this DoD mandate for a witness needs to be removed. Rather than protecting human subject's rights, it actually violates both the privacy and confidentiality of the Native patient. It is also based on middle-class standards of having multiple phones available in a household, which is not necessarily valid for low income households.

We feel we can successfully implement the informed consent process and protect the human rights of privacy of our participants. This witness is an intrusion to the confidential nature of the informed consent process and is proving to be a barrier to recruitment to the study and subsequently to attaining our project goals.

b. Intake forms are submitted to Rick Clark of Morning Dew Productions for data loading and correction. Estimate 100 intakes in Year 1, 200 in years 2 and 3.

Contrary to direct instruction from the P.I., during this last year, the former Network Director insisted on loading the consent and survey data and has not submitted the raw / hard copies to NACR headquarters. She has been removed from the project and current staff and contractors are in the process of re-collecting all data collected by her. This has resulted in a significant delay and we have requested legal counsel to assist us in obtaining any raw data currently in her possession. Judy Hariton remains the project coordinator and is training more people on the informed consent and survey data collection and submission process.

c. Dr. Dignan verifies accuracy of data entry by randomly selecting 10% sample of intake forms and performing an independent data load. Inconsistencies will be discussed and re-training will occur. If deemed necessary.

Dr. Burhansstipanov has verified data quality for the initial 50 intakes loaded into the program. We discovered some computer programming errors which have been corrected. Dr. Dignan will conduct subsequent data quality by randomly selecting a 10% sample of intakes and reloading the information to confirm accuracy of input.

d. Link Native Americans to related on-going projects – Native American breast cancer support resources and services (i.e., link with a telephone support Sister, the six culturally relevant support booklets, videos, pre-paid long-distance phone cards).

All support materials mailed to Native patient participants and referral to additional support has continued. This aspect of the project is much greater than was originally anticipated. Almost all of the survivors need additional assistance. Most are not receiving quality care (e.g., lumpectomy without radiation). Several have transportation challenges to obtain care. Many have child care issues (e.g., the patient is a single parent or the partner works away from home for several weeks at a time). The co-morbidity is high among this population. Diabetes, arthritis, high blood pressure and drug-dependence are common conditions. The coordinator of the Network continues to use local, regional and national resources to help the women find assistance for these additional problems (e.g., <http://www.needymeds.com>).

Task 3. Collection of medical records and verification of self-reported data, Months 4-33.

a. Review and modify, if necessary, the medical record abstract protocols used for Alaska Native Tumor Registry

The Alaska Native Tumor Registry medical record abstraction protocols were reviewed by the P.I. and found to be insufficient and included recommendations that initially led to excessive errors. The greatest difficulty was the inability to track from the time of diagnosis to treatment and side effects of treatment / disease. The former Director of the Network and the P.I. reviewed medical records for Alaska Native survivors and discovered serious, incomplete, inaccurate data recording. Likewise, medical records were reviewed at selected rural clinics and found to be insufficient (e.g., cancer medical records on 5" X 8" index cards and tossed in lower right-hand drawer of hospital staff's desk ... cancer information was not stored in the hard copy of the medical record for 2 of these clinics).

In a totally unrelated project, an oncology professional working at one of the largest IHS-based health care facilities for referral of cancer patients from the contingent 48 states had the hospital staff review all medical records for 2000-2001. Of 300 cancer-patient medical records, over half included ICD-9 coding errors, omission of significant cancer information (e.g., histologic grade not transferred from pathology reports to the medical records), and unreadable information. This clinic has been reported to have quality data management. The hospital administrator and IHS headquarters west were informed of feasible strategies for correcting the medical record and data loading errors. To date none of the strategies have been implemented.

b. For those survivors who agreed to have copies of medical records sent to the Survivors' Network, the site coordinators will request copies of medical records. A \$15 fee will be sent to the medical provider's office to cover photocopying expenses and staff time to copy files. Estimate 75 survivors in year 1(e.g., delay of receipt), 175+ in Year 2, and 225+ in year 3.

Based upon the issues with medical records reported in each annual report, and in light of the variable interpretation of HIPPA requirements, NACR removed the section from the informed consent process requesting copies of cancer-related medical records. Of the medical records collected by NACR Headquarters, almost none included information to validate staging (i.e., metastases, histologic grade, lymph node involvement).

c. Pull relevant data (e.g. staging, histologic grade, recommendations for treatment, recommended site follow-up care) from medical records and load into survivors database.

Of the records collected, most, but not all had treatment specified, but no staging information was included. The P.I. traveled to selected clinics and interviewed health care providers about the medical records issues to discuss strategies suggested by other local professionals (i.e., the strategies did not emanate from the P.I. but she was asked by the hospital staff to attempt to get the suggestions implemented) for resolving the errors. Likewise during July 2001, she met privately with data managers for one of the lead health care settings for cancer care in Indian Country. The conclusions from the former was that until the hospital administrators were willing to admit the problems existed, no strategies could be implemented. For the latter, the data manager identified additional problems within the RPMS IHS data management system that were likely to make accurate conclusions even more challenging. This data manager had suggested programming changes that could result in more accurate RPMS report summaries to the hospital administrators, but has not yet been allocated additional staff resources to write and implement this program. This data manager is interested in seeing these corrections made.

Task 4: Refine database, Months 9-33.

- a. **Based on preliminary data runs, review data at six months after data collection was initiated to determine database problems while the number of Native Americans in the database is still small enough to be manageable. Month 09.**

This was accomplished. We found we had to modify the response fields for several questions by allowing more space for explanations. Few data entry errors were identified. Some of the sequencing of the computer data screens also required refinement. Mr. Clark revised the program within a few days of the problem being identified. During 2001, Dr. Dignan indicated the desire to begin using ACCESS rather than the other program and this change is in progress.

- b. **Based on the PI and co-investigators' recommendations, determine which cross tables should be run and when they should be run.**

We have conducted some preliminary frequency runs and among the cross tabulations we will conduct are the following variables:

1. age at diagnosis and stage at the time of diagnosis
2. date of last breast health screening and stage at the time of diagnosis
3. private health care / Medicare insurance compared with IHS CHS cancer care
4. urban and reservation-based
5. health care coverage (variables #3) and stage at diagnosis
6. health care coverage (variables #3) and interval from biopsy to initiation of cancer care
7. stage at the time of diagnosis and standard of care received (NCI PDQ)

- c. **Product data run every six months to review accuracy of data and preliminary indications of trends that should be closely documented.**

We began frequency data runs in April and July 2001. Preliminary trends are age at the time of diagnosis, access to private health care insurance, intervals between biopsy and initiation of treatment.

Task 5. Evaluation of the Database, Months 24 -36

- a. **PI and co-investigators produce cross tabulations and run preliminary statistical analysis. Advisory Board reviews and makes recommendations for additional statistical calculations.**
- b. **Preliminary data summarized and included in National Indian Health Board quarterly newsletter. Press releases of other data, as well as clarification that it is only preliminary, be disseminated to tribal newspapers and magazines.**

- c. **Preparation and submission of (1) papers for Tribal Communities; Native (lay population and providers) meetings (e.g., Association of American Indian Physicians, National Indian Health Board Annual Consumers' Meeting, Native Wellness and Women Conference, Society for the Advancement of Chicanos and Native Americans in Sciences, American Indian Science and Engineering Society, IHS Annual Research conference); (3) professional meetings for presentations (e.g., American Public Health Association; ASPO, Endocrine Society Annual Meeting); and (4) professional peer-reviewed journals and publications (e.g., Cancer, Epidemiology).**
- d. **Submission of final report to DOD.**

Since NACR staff and contractors are in the process of re-collecting and re-loading all data collected since March 2002, we have not preformed any additional data runs.

6. Key Research /Preliminary Findings

- o Approximately one-fourth of the Native breast cancer survivors have diabetes in addition to their breast cancer. Their oncologist and diabetes physicians almost never have any interaction and the subsequent treatments for both diseases frequently interact adversely with one another (e.g., kidney and circulation problems associated with concurrent glucose controlling medication and chemotherapy).
- o Less than one-third of the Native survivors have health insurance -- regardless of whether they live in the urban or rural community.
- o A factor which is adversely affecting quality of care is access to private insurance versus use of Indian Health Service (IHS) Contracted Health Services (CHS). The interval from biopsy to initiation of cancer care is more than six months in selected tribal communities. This varies greatly from location to location, and is in part dependent upon (a) IHS/Tribal clinic; (b) calendar month of the year (i.e., CHS monies frequently are depleted by June for most clinics); (c) tribal priority ranking of cancer for CHS monies (i.e., if prioritized lower than 8, the patient may not be referred at all); (d) daily living issues unrelated to availability of CHS monies (e.g., single mother responsible for small children who may be gone for 3-6 months to complete the treatment cycle needs to find someone to care for the children during her absence).
- o The norm for CHS referred patients is no access to a second opinion for their diagnosis.
- o To date, almost half of all of the breast cancer patients have been identified with cancer prior to age 50, which may indicate a different pattern of cancer in comparison to white women.

7. Reportable Outcomes

- a. During November 2001, NACR sponsored the first national Native American Cancer Survivors' Support Conference in Scottsdale, Arizona (report is available on our web site). As a result, the following articles are in submission which are related to the "National Native American Cancer Survivors' Support Network":
 - 1) Restivo TS, Weiner D, Burhansstipanov L, Krebs LU. From survivorship to thrivership: Native peoples weaving a healthy life with cancer. Resubmitted January 2003 to *Cancer*.
 - 2) Burhansstipanov L, Krebs LU, Bradley A, Gamito E. Lessons Learned while Developing "Clinical Trials Education for Native Americans" Curriculum. Resubmitted January 2003 to *Cancer*.
- b. Burhansstipanov L, Gilbert A, LaMarca K, Krebs LU. An innovative path to improving cancer care in Indian Country. *Public Health Reports*. 2002; 116: 5: 424-433.

- c. Burhansstipanov L and Hollow W. Native American Cultural Aspects of Nursing Oncology Care. *Seminars in Oncology Nursing*: 2001; 17: 3: 206-219.
- d. Burhansstipanov L. Chapter 10: Cancer: A Growing Problem. eds. Mim Dixon and Yvette Roubideaux. *Promises to Keep*. Washington, D.C., American Public Health Association, 2001.

Patents and informatics are not appropriate to this study.

8. Conclusions

Although the process for this Network is quite unique from support programs implemented within other cultures, this project is gradually increasing the size of the cohort and we feel that we will be successful in creating a survivors database and being able to document patterns of cancer care among Native American breast cancer patients. This cohort will serve to develop and implement quality of life interventions designed to improve both the quantity and quality of life of the cancer patient and her/his family.

9. References

10. Appendices

Peer Reviewed publication since the submission of the previous annual report: Burhansstipanov L, Gilbert A, LaMarca K, Krebs LU. An innovative path to improving cancer care in Indian Country. *Public Health Reports*. 2002; 116: 5: 424-433.

11. Binding. As per DoD instructions, this report is stapled in upper left hand corner and is camera-ready.

12. Final Reports

- a. **Meeting Abstracts** The Native American Breast Cancer Survivors' Support Network has been presented at the following meetings:

1999 (Presentations in Chronological Order)

- Presented, "Native American Breast Cancer Support -- Training Outreach Workers". Rincon Rancheria, Pauma, CA. January 5-6, 1999.
- Presented, "Native American Breast Cancer Survivors' Support Network." National Susan G. Komen Breast Cancer Foundation Affiliate Meeting, Dallas, TX. February 5, 1999.
- Presented a poster on, "Native American Breast Cancer Survivors' Support Network." for the National Cancer Institute Office of Cancer Survivorship Annual Conference. Washington, DC. March 8-9, 1999.
- Presented, "National Native American Breast Cancer Survivors Support Network" to the Network for Cancer Control Research among American Indian and Alaska Native Populations, supported by the NCI. Washington, DC. April 9-10, 1999.
- Presented, Native American cancer survivor: how the community can help. Rincon Reservation, CA May 19, 1999.
- Presented, "National Native American Cancer Survivors Support Network" to the Northwest Portland Area Indian Health Board. Reno, Nevada. July 15, 1999.
- Presented, "National Native American Cancer Survivors' Support Network" CDC Challenges of Comprehensive Cancer Control. Atlanta, GA. September 9, 1999.
- Presented, "National Native American Cancer Survivors' Support Network" to the National Susan G. Komen Breast Cancer Foundation Grantee's Conference. Dallas, TX. October 4, 1999.

- Presented, "National Native American Cancer Survivors' Support Network" American Public Health Association. Chicago, IL. November 8, 1999.

2000 (Presentations in Chronological Order)

- Presented, "Cancer," to the Native Elder's Research Center (NERC), Resource Center for Minority Aging Research (RCMAR), University of Colorado Health Sciences Center, Denver, CO. January 9, 2000.
- Co-Presented with Terrie Restivo, "National Native American Cancer Survivors' Support Network" to the 7th Biennial Symposium on Minorities and Medically Underserved Populations and Cancer. Washington, D.C., February 12, 2000.
- Co-Presented with Alisa Gilbert, "National Native American Cancer Survivors' Support Network" to the University of Oklahoma's Wellness and Women Conference. San Diego, CA. March 22, 2000.
- Presented, "Native American Culturally Competent and Community Driven Research" to the OHSU Native American Cancer Researchers' Training Program. March 23, 2000.
- Presented, "Native American Health Issues, Lessons Learned from Community-based Interventions, and Overview of Native Cancer Projects" to the University of North Carolina Summer Public Health Research Videoconference on Minority Health, NC. June 12, 2000.
- Presented, "Native American Cancer Research and Community-Driven Interventions" to the National Cancer Institute Research Fellows, Rockville, M.D.. August 1, 2000.
- Presented, "National Native American Cancer Survivors' Support Network: what works and what does not." National Susan G. Komen Breast Cancer Foundation Grantee meeting. Washington, D.C., September 17-18, 2000.
- Presented on panel for town hall meeting, "Issues Facing the Underserved in Breast Cancer: Native Americans." National Susan G. Komen Breast Cancer Foundation Grantee meeting. Washington, D.C., September 19, 2000.
- Presented, "Native American Cancer Issues". CH 509 Graduate Seminar in Health Behavior, University of Northern Colorado, Greeley, CO, November 7, 2000.
- Presented, "National Native American Cancer Survivors' Support Network: Preliminary Data" American Public Health Association, Boston, MA, November 13, 2000.

2001 (Presentations in Chronological Order)

- Presented, Training #1 for "Native American Breast Cancer Support in Southern California Indian Communities." Rincon Reservation, CA, January 8-9, 2001
- Presented, "National Native American Cancer Survivors' Support Network" Intercultural Cancer Council National Network, Washington, DC. February 6, 2001
- Presented, "National Native American Cancer Survivors' Support Network: Preliminary Findings." University of Oklahoma's Wellness and Women Meeting, San Diego, CA March 5, 2001
- Presented, Training #2 for "Native American Breast Cancer Support in Southern California Indian Communities." Barona Reservation, CA, March 8, 2001
- Facilitated and presented multiple sessions during 3 day, "CDC Tribal Outreach Training," (which included preliminary data about Native American breast cancer survivors), Denver, CO, May 2-4, 2001
- Presented, "Native American Cultural Issues affecting Cancer Pain Relief." (which included preliminary data from the Native American breast cancer survivors), American Alliance of Cancer Pain Initiatives, Madison, WI, June 14, 2001.
- Presented, "Native American Cancer Research Cultural Issues." National Cancer Institute Research Fellows Training. Bethesda, MD. July 31, 2001
- Presented poster, "National Native American Cancer Survivors' Support Network". Association of American Indian Physicians, Albuquerque, NM. August 11, 2001.
- Presented poster, "National Native American Cancer Survivors' Support Network". Centers for Disease Control and Prevention 2001 Cancer Conference. Atlanta, GA. September 5-7, 2001.

- Presented, "Preliminary Data from the 'National Native American Cancer Survivors' Support Network" American Public Health Association, Atlanta, GA, October 22, 2001.
- Presented, "Clinical Trials Education for Native Americans" American Public Health Association, Atlanta, GA, October 23, 2001.
- Co-Presented, "Preliminary Data from the 'National Native American Cancer Survivors' Support Network" Native American Cancer Survivors' / Thrivers' Conference. Scottsdale, AZ, November 9, 2001.
- Presented, "Clinical Trials Education for Native Americans: Native cancer patients have a right to choose." Native American Cancer Survivors' / Thrivers' Conference. Scottsdale, AZ, November 9, 2001.
- Co-Presented with Judith Kaur, "Clinical Trials Education for Native Americans." 5th National Native American Cancer Conference: Changing Patterns" Scottsdale, AZ, November 12, 2001.
- Presented, "Preliminary Data from the 'National Native American Cancer Survivors' Support Network" 5th National Native American Cancer Conference: Changing Patterns" Scottsdale, AZ, November 12, 2001.
- Co-Presented with Mark McClees and Rick Strickland (substituted for Mark Dignan who was ill), "The Native IRB Process". 5th National Native American Cancer Conference: Changing Patterns" Scottsdale, AZ, November 13, 2001.

2002 (Presentations in Chronological Order)

- Presented, "Community-driven interventions", Cancer Cultural and Literacy Institute Training (included preliminary findings from the "National Native American Cancer Survivors' Support Network"), Clearwater, FL, January 8, 2002
- Presented, "Cancer among Native Americans: Emerging Patterns of Disease and Disparities in Accessing Care," (included preliminary findings from the "National Native American Cancer Survivors' Support Network") for the Carnival Cruise Fund-raising event for American Cancer Society and Native American Cancer Research. California and Mexico. February 1, 2002.
- Presented "Clinical Trials Education for Native Americans: Lessons Learned" (included preliminary findings from the "National Native American Cancer Survivors' Support Network"). 8th Biennial Symposium on Minorities, the Medically Underserved and Cancer. Washington, D.C. February 7, 2002.
- Presented poster for the "National Native American Cancer Survivors' Support Network" 8th Biennial Symposium on Minorities, the Medically Underserved and Cancer. Washington, D.C. February 9, 2002.
- Presented, "Clinical Trials Education for Native Americans" at the Native Wellness and Healing Institutes "All my Relations" conference, Reno, NV, February 25, 2002.
- Assisted / mentored Ms. Terrie Restivo in her presentation, "Native American Cancer Survivor Support Circles" (included preliminary findings from the "National Native American Cancer Survivors' Support Network") for the Native Wellness and Healing Institutes "All my Relations" conference, Reno, NV February 27, 2002.
- Taped presentation for Dr. Lori Jervis' Life Planning Teleconference class, "Cancer and Native Americans," (included preliminary findings from the "National Native American Cancer Survivors' Support Network") Denver, CO March 20, 2002.
- Judy Hariton, Network Coordinator, presented poster session for American Association for Cancer Research's Survivor Program. March 20, 2002.
- Presented keynote, "Diversity and Women's Health Issues" University of Nebraska's Women's Health Conference (included preliminary findings from the "National Native American Cancer Survivors' Support Network"). April 5, 2002.
- Presented general session, "Community-based Health Interventions" (included preliminary findings from the "National Native American Cancer Survivors' Support Network") University of Nebraska's Women's Health Conference. April 5, 2002.

- Presented 2-day training for southern California, "Helping Path" tribal programs on cancer clusters, leukemia, new treatments, non-profit processes and preliminary findings from the "National Native American Cancer Survivors' Support Network". Rincon Tribal Center, CA. May 20-21, 2002.
- Alisa Gilbert presented poster session, NIH "Cancer Survivorship: Resilience Across the Lifespan", Hilton Washington & Towers Hotel, Washington, D.C., June 2-4, 2002.
- Presented 2 ½ day training to help the states improve their working relationships with tribal Nations and programs (included preliminary findings from the "National Native American Cancer Survivors' Support Network"). Albuquerque, NM. June 11-13, 2002.
- Presented via teleconference, "Community-based Interventions: Making the Messages Work" (included preliminary findings from the "National Native American Cancer Survivors' Support Network") to the Oregon Health Sciences University, "Native Cancer Researchers Training Program". Portland, OR. June 20, 2002.
- Presented, "Cancer among Native Americans" for the NCI's fellows course, "The Principles and Practice of Cancer Prevention and Control." (included preliminary findings from the "National Native American Cancer Survivors' Support Network") Rockville, MD. July 29, 2002.
- Presented, "American Indian Alaska Native Cancer Update" for the CDC Tribal Program Directors, Anchorage, AK, July 30, 2002
- Co-presented with Alisa Gilbert, "Cancer Education Resources,"(included preliminary findings from the "National Native American Cancer Survivors' Support Network") for the Alaska Cancer Conference, Anchorage, AK July 31, 2002.
- Presented, "Clinical Trials Education for Native Americans" for the Association for American Indian Physicians, Anchorage, AK August 2, 2002.
- Presented, "Disparities and cancer care among Native Americans" (included preliminary findings from the "National Native American Cancer Survivors' Support Network") to the Annual Colorado Cancer Conference, Colorado Springs, CO August 22, 2002.
- Facilitated and key trainer for the National Indian Women's Health Resource Center's CDC Tribal Outreach Training, (included preliminary findings from the "National Native American Cancer Survivors' Support Network") Portland, OR August 27-29, 2002.
- Judy Hariton presented poster session to Era of Hope Department of Defense Breast Cancer Research Program Meeting, Tampa, FL, September 29, 2002.
- Presented keynote, Understanding Cancer (which included preliminary findings from the "National Native American Cancer Survivors' Support Network", Shakopee Mdewakanton Sioux Community Cancer Conference, Prior Lake, MN, October 7, 2002.
- Presented, "Clinical Trials Education for Native Americans: Lessons Learned" at the American Public Health Association Annual Conference, Philadelphia, PA, November 11, 2002.

2003 (Presentations in Chronological Order)

- Presented with Nina Wampler, "National Native American Cancer Survivors' Support Network" to the Native Men and Women's Wellness Conference, Mesa, AZ, February 12, 2003.
- NACR Staff displayed exhibit highlighting the "National Native American Cancer Survivors' Support Network" throughout the Native Men and Women's Wellness Conference, Mesa, AZ, February 12, 2003.

b. Articles in Peer Reviewed Journals

- 1) Burhansstipanov L, Gilbert A, LaMarca K, Krebs LU. An innovative path to improving cancer care in Indian Country. *Public Health Reports*. 2002; 116: 5: 424-433.
- 2) Burhansstipanov L and Hollow W. Native American Cultural Aspects of Nursing Oncology Care. *Seminars in Oncology Nursing*: 2001; 17: 3: 206-219.

- 3) Burhansstipanov L. Chapter 10: Cancer: A Growing Problem. eds. Mim Dixon and Yvette Roubideaux. *Promises to Keep*. Washington, D.C., American Public Health Association, 2001.

c. Personnel Receiving Partial Pay for the Research Effort

Name	Role on Project	Native American
Linda Burhansstipanov, M.S.P.H., Dr.P.H.	P.I.	yes
Lisa Castro	Grants Manager	
Richard E. Clark	Data / Computer Programming; <i>no longer in this role</i>	
Mark Dignan, Ph.D.	Co-Investigator / Data Manager	
Alisa Gilbert	Director: <i>no longer in this role</i>	yes
Judy Hariton	Coordinator	
Tvhokne Harjo	Data coding and loading; <i>no longer in this role</i>	yes
Khari LaMarca, M.P.H.	Survivor Advocate; <i>no longer in this role</i>	yes

Advisory Board members and Survivor Advocates who receive partial compensation for work performed for the Network

Name	Role on Project	Native American
Alice Bradley, MA	Advisory Board – in kind contribution	
Jennie Joe, PhD	Advisory Board / Survivor	Yes
Judith S. Kaur, M.D. oncologists	Advisory Board	Yes
Linda Krebs, RN, AOCN, Ph.D.	Advisory Board	
Jody Pelusi, RN AOCN, PhD	Survivor Advocate	
Terri Restivo	Survivor Advocate / Survivor	Yes
Jo Stand	Survivor Advocate/ Survivor	Yes
Caren Trujillo	Survivor Advocate / FDR	Yes
Evelyn Trujillo	Survivor Advocate / Survivor	
Nina Wampler	Survivor Advocate / FDR	Yes
Diane Weiner	Survivor Advocate / Faculty	